



Exploring experiences of vaccine-related and alternative treatments for individuals with autism: A qualitative study

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ABSTRACT

Some alternative treatments wrongly suggest that routine childhood vaccines cause autism resulting in vaccine skepticism and false claims about curing autism. In the present study we explore the experiences of vaccine-related and alternative treatments of autistic individuals. Semi-structured interviews were conducted with autistic adults ($n = 3$), parents of autistic children ($n = 5$) and parents of autistic adults ($n = 5$). Thematic analysis showed five themes: (1) reasons for choosing alternative treatment, (2) treatment content, (3) experiences with alternative care, (4) outcomes of the vaccine-related treatment and (5) future directions for treating autism. Both positive (holistic approach, time and attention) and negative aspects (false claims about vaccines and curability of autism) were found. Improved support and guidelines could reduce ineffective and harmful alternative treatments for autism.

Autism Spectrum Disorder (ASD, from here on autism as per Bottema-Beutel et al. (2021)) is a heterogeneous neurodevelopmental disorder characterized by social communication impairments, restrictive and repetitive behaviors and/or interests, and sensory issues (American Psychiatric Association, 2013; Lord et al., 2020). Autism occurs in around 1 % of the population and the majority of autistic children (we use a combination of person-first and identity-first language as per Buijsman et al. (2022)) have at least one comorbid diagnosis (Lord et al., 2020; Simonoff et al., 2008). Research evidence shows that individuals with autism are more likely to use alternative treatments (sometimes referred to as 'complementary and alternative treatments' or CAM) than individuals from other clinical groups (Höfer et al., 2017). Alternative treatments can be harmful to individuals with autism as they may result in vaccine skepticism and present false claims about curing autism (Dubé et al., 2013; Höfer et al., 2017). Some treatments approaches (such as

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CEASE therapy; <http://www.cease-therapy.com>) suggest that autism is (partly) caused by routine childhood vaccines such as the MMR-vaccine and can thus be cured by erasing the effect of these toxic substances. This study aimed to explore the experiences of autistic individuals with vaccine-related treatments and alternative treatments.

Since the widely refuted refrigerator mother theory of autism (Douglas, 2014), linking autism to uncaring parenting style, many other explanations of autism have been suggested, including the links with assisted reproductive technologies, prenatal smoking and cesarean sections (Davidson, 2017; Lord et al., 2020). No evidence has been found in favor of these theories (Lord et al., 2020). One of the most persistent false theories on autism includes childhood vaccinations (Plotkin et al., 2009). Despite multiple studies that showed no evidence for a link between autism and vaccinations (Taylor et al., 2014) and compelling evidence to suggest that autism results from genetic and environmental interactions (Lord et al., 2020), the suggestion that vaccines cause autism proves difficult to eliminate.

Alternative treatments are defined by their contrast to guideline treatments. There are several national and global guidelines for autism treatment published by institutes and societies for mental health and psychiatry (Centers for Disease Control and Prevention (CDC), 2019; Fuentes et al., 2020); GGZ (Standaarden, 2020; National Institute for Health and Care Excellence (NICE), 2013). These guidelines include recommendations for the treatment of autism based on public and expert opinion. American and European (Netherlands, UK) guidelines agree that autism treatment should consist of early social and communicative interventions, psycho-education and other conventional treatments and medication to reduce co-morbid problems and improve overall health. These treatments integrate well-grounded theoretical and empirical backgrounds, and are used in clinical practice (in the region that the guidelines are from). We will refer to this group of treatments as mainstream treatments or mainstream care, as this is also the terminology used in the study and by the participants. It should be noted that there is concern about some of the mainstream treatments, including Applied Behavior Analysis (ABA), and the neurodiversity movement has emphasized the need for more neurodiversity affirming support (Leadbitter et al., 2021).

In the Netherlands, no specific laws focus on the regulation of alternative treatments (for autism). A relevant legislative framework may also affect these treatments and healthcare providers. The BIG Act (law of professions in individual health care) offers some protection against unauthorized practitioners, however, the responsibility for choosing and using alternative treatment largely rests with the patient and their healthcare providers (Inspectie Gezondheidszorg en Jeugd, n.d.). In addition to mainstream treatments, many alternative treatments are available for autistic individuals of all ages, ranging from elimination diets and homeopathic remedies to massages and hypnosis therapy (Lofthouse et al., 2012). There is some evidence that alternative treatments in general can have beneficial effects on mental health problems; for example, relaxations methods can help with stress-related symptoms and specific herbal remedies can alleviate/ease anxiety, depression and insomnia symptoms (Wang et al., 2018). However, there is a lack of consensus about the effectiveness of alternative treatments in improving core autism symptoms (Fuentes et al., 2020; Wang et al., 2018).

Vaccine-related treatments suggest a causal link between autism and (childhood) vaccines. The vaccines are supposed to disrupt the child's development, and the treatment aims to 'cure' this process. An example of such a treatment is CEASE-therapy (Complete Elimination of Autism Spectrum Expression; <http://www.cease-therapy.com>). This treatment uses homeopathy including dilutions of vaccines to erase the effects of the vaccine substance in the body (this method is also called isopathy). Different names are used to describe these vaccine-related treatments including homeopathic detox therapy, isotherapy and homeopathic prophylaxis. Besides being ineffective, vaccine-related treatments could have other negative consequences. They often claim – without any evidence – that homeopathic treatment can *cure* autism which contributes to the spread of misinformation and creates an unwanted expectation of a cure for autism. Although there are no rules against providing these types of treatment in the Netherlands, the government and health authorities strongly advocate for conventional vaccination programs (Rijksinstituut voor Volksgezondheid en Milieu, n.d.).

Generally, individuals using alternative treatments for mental and/or physical health issues are looking for a holistic and natural approach (Doering et al., 2013; Keene et al., 2019; Wang et al., 2018). The use of alternative treatments also runs in the family, as often parents may be passing their preference onto children (Doering et al., 2013; Wang et al., 2018) or family or friends advising alternative treatments (Keene et al., 2019; Wang et al., 2018). Specific reasons mentioned in the literature include the aim to improve physical or emotional wellbeing (Keene et al., 2019), the belief in the effects of alternative treatments or the discontent with (side effects of) conventional treatments (Keene et al., 2019; Wang et al., 2018) and wanting to feel like they have tried all available options (Keene et al., 2019). Parents also report that they often feel overwhelmed by the amount of information they receive about the variability and diversity of treatment options for autism (Frame and Casey, 2019).

A factor that can influence treatment choice is the parents or individual's belief about what autism is and what causes it, i.e., their explanatory model (Kleinman, 1980). It is likely that claims made by alternative practitioners can affect parents' explanatory models of autism. Especially given that mothers of autistic children (and the family system as a whole) can be under significant stress while caring for a child with autism (DePape and Lindsay, 2015; Papadopoulos, 2021). Studies have shown that parents caring for a child with autism often encountered all kinds of challenges such as poor communication with health care providers or treatments not being covered by health insurance (DePape and Lindsay, 2015). Another qualitative study (Edwards et al., 2018) has shown that the factors influencing treatment choice tend to change over time as the parents evolve from parents to experts. At first parents have high expectations of treatments. However, over time parents start to better understand and accept their child's autism and focus more on the child's specific needs (Edwards et al., 2018). Overall, treatment choice is a multifactorial outcome based on several factors ranging from parental beliefs to autism psychoeducation.

There is little knowledge about the personal experiences of autistic individuals with vaccine-related treatments. A previous study that surveyed nearly 2000 individuals with autism in the Netherlands (Jonkman et al., 2022) found that alternative treatments are still widely used (30.7 % of individuals with autism of all ages, 46.4% of autistic children). Vaccine-related treatments were reported in 3.2 % of all ages and 6.7 % of children, amounting to around 1860 children in the Netherlands who received a vaccine-related treatment in

the last five years (Jonkman et al., 2022).

In the current study we aim to explore and gain an in-depth understanding about the lived experiences of individuals with autism who receive alternative and vaccine-related treatments. With the use of semi-structured interviews, we aimed to understand this group's personal narrative and motivation. We examined the effect of the possible harmful aspects of these treatments including the unfounded link between autism and vaccines and the claim that this sort of treatment can cure autism. We aimed to understand these families' choices and gain a broader perspective about how their attitude towards these treatments has been shaped.

1. Methods

1.1. Procedure

We conducted 13 qualitative semi-structured interviews with three groups: (1) adults presenting with autism, (2) parents of autistic children and (3) parents of adults with autism (serving as their legal representative). Purposive sampling was used, based on participants' answers on a self-report questionnaire (including questions about treatment satisfaction (on a 5-point scale), whether the practitioner mentioned vaccinations or the possibility of curing autism (both yes/no questions) and possible harm from the treatment (yes/no question) from a previous survey study (Jonkman et al., 2022). To ensure enough participants with negative experiences were included, KJ invited participants for an interview in a consecutive manner: (1) participants who had been harmed or were dissatisfied with the treatment (3 participants), (2) participants who were neutral or whose practitioner had mentioned either vaccinations or the possibility of curing autism (6 participants), (3) participants who were satisfied with the treatment (4 participants). We also tried to achieve variety in gender and informants (adults, parents and legal representatives).

1.2. Participants and recruitment

The 13 interviewees were sampled from 64 individuals with autism (mean age = 24.9, $SD = 17.1$, 59.4 % males) from a previous study conducted in the Netherlands (Jonkman et al., 2022). Participants were eligible to participate in this interview study if they met the following inclusion criteria: They were either (1) an adult (16+) with autism, (2) a parent of a child younger than 16 years old with autism or (3) the legal representative (this can be a parent) of an adult with autism; they (or their child) had used a vaccine-related treatment; they had given written consent to be contacted for a follow-up interview. Participants were not excluded if they had comorbid health conditions. Three types of informants (adults, parents and legal representatives) were included to gain a systemic understanding of the topic by looking at each group's perspective and considerations when choosing alternative treatments. Adults could report on both treatment received in childhood and in adulthood. The interviewees included three adults with autism, five parents of autistic children and five parents of adults with autism. The average age of the individuals with autism was 20 years old and the average age of diagnosis was 6.5 years old (See Table 1 for demographic information of the participants).

1.3. Materials

This study used a semi-structured interview protocol with 21 questions. Interviews were conducted online through Zoom because

Table 1
Demographic information of the participants (n = 13).

Variable	
Age of person with autism (in years)	
Mean (SD)	20.00 (7.28)
Range	10–32
Age of diagnosis (in years)	
Mean (SD)	6.46 (4.58)
Range	2–18
Sex of person with autism	
Male	61.53 %
Female	38.46 %
Comorbidity	
> 1 other diagnosis	46.15 %
Intellectual level	
IQ below 70	30.77 %
Reporter	
Self-report	23.08 %
Parent-report (all mothers)	38.46 %
Legal representative-report	38.46 %
Mainstream treatment used	
Only interventions	38.46 %
Only medication	15.35 %
Both interventions and medication	15.38 %
None	30.77 %

of COVID-19. The interviews explored participants experiences with alternative treatments for autism focusing on vaccine-related treatments. Interview questions focused on the route to the treatment (e.g.: “Can you tell me more about how you found this treatment?”), the treatment content (e.g.: “What happened during the treatment?”), satisfaction (e.g.: “How did you experience the treatment?”), damage, costs and insurance (e.g.: “Can you estimate the total costs of the treatment?”), general experiences and views on alternative treatments for autism (e.g.: “Why do you think people turn to non-mainstream or alternative treatments?”) (See Appendix A for the interview guide). Questions were designed in collaboration with individuals with autism (2), individuals who have experience working with autistic individuals (1) and researchers specialized in autism (3) and qualitative research (1). Feedback was obtained both in collaborative meetings and through email correspondence. We aimed to formulate the questions open and unbiased wherever possible, to stimulate participants to expand on their experiences. Some more direct questions were included to explore specific interests of the researchers regarding the possible negative effects of the vaccine-related treatment, such as “What did the practitioner tell you about the possibility that the treatment would cure autism?”. The interview protocol was piloted with a parent of a child with autism who had followed several alternative treatments. Between interviews the interview protocol was edited or expanded on where needed. The phrasing of some questions was refined and general questions about alternative care were added (see Appendix A).

1.4. Data collection

Eligible participants were sent an email inviting them to participate in the study. The email provided some information about the objectives and procedure of the interview as well as the guarantee that participants would remain anonymous. The date and time of the interview were decided in correspondence with the participant. Interviews were conducted by KJ between the 8th of April 2021 and the 20th of May 2021. The interview duration ranged from 30 to 70 min. All interviews were audio-recorded with the participants’ verbal consent. Participants were given the opportunity to ask questions about any part of the study both before the interview started and after the recording ended. Audio-recordings were sent to research assistants who transcribed the interviews. The files were sent through SurfFileSender and were encrypted and password protected. All identifying information was removed from the transcriptions to ensure anonymity of all participants.

1.5. Data analysis and interpretation

Data was analysed thematically (Braun and Clarke, 2006; Byrne, 2022; Clarke and Braun, 2017) as thematic analysis deepens understanding of the lived experience of participants based on identified patterns. First, transcripts were checked for accuracy against the recordings and corrected where needed by KJ. KJ read the transcripts several times and became familiar with the data. Secondly, an initial codebook was developed by KJ and LB, these initial codes were pertinent to the first three interviews which were coded independently. Reviewers met to discuss any discrepancies and for further clarifications. Line-by-line coding was used looking for both similarities and differences in emerging patterns. Coding was both inductive and deductive. Some codes were predetermined based on the research questions; others were data-driven based on similarities in the topics brought up by the interviewees. Examples of codes are: “Mainstream care falls short”; “Effect of the treatment” and “A lot of time and attention”. The codebook was reviewed and updated throughout the study by MA and KJ and the refinement of codes based on the topics brought up during the newly conducted interviews was discussed. This reiterative analytical process allowed for new meanings of the data (Byrne, 2022). KJ coded all interviews and then discussed with the wider research team. The coding of the interviews was prepared with ATLAS.ti software. MA coded and discussed 15 % of the interviews with KJ. The inter-rater reliability (IRR) was based on percent agreement of the codes ascribed to extracts. The IRR was 73.3 % between KJ and MA. Based on MA’s feedback some codes were added or deleted and the possibility of expanding extracts was discussed. KJ refined the coding based on this feedback.

Thirdly, when all interviews were coded, potential themes were formulated by KJ in consultation with LB, MA and SB. Fourthly, the themes were discussed and reviewed by all researchers. Based on this discussion, some themes were refined and some extracts were placed under different subthemes, for example the subtheme ‘positive experiences’ was made by merging ‘more attention’ and ‘friendly practitioners’. All data was read again, some subthemes were changed or merged, and any additional data extracts were added to the themes. Fifthly, all themes were defined and refined by looking at the themes’ data extracts. The themes were named based on the overall story of the analysis and accompanied by narratives that explained how and why each theme is relevant. Lastly, the report of the analysis was written. Quotes that illustrated the themes and subthemes best were chosen for the report and translated by KJ.

Given that the aim of this study was both exploratory and experiential, the epistemological framework employed was a contextualist approach (Braun and Clarke, 2006). The explanatory model (Kleinman, 1980) is aligned with this epistemological framework of contextualism and how lived experiences in the social context shape the decisions individuals make about treatment. Participants’ experiences may be shaped by social environmental stimuli and in this case influenced by parents, family, friends regarding choice treatment (constructionist approach) and also by personal experiences with services (realist approach) which could have led to positive or negative views about vaccines.

1.6. Ethical considerations

The interview transcriptions were anonymized, each participant received a number as a pseudonym. This number was used to refer to the participants in all documents related to the study. The list linking names to pseudonyms was not shared and password protected. This study was approved by the Standing Committee of Science and Ethics (VCWE) of the Vrije Universiteit Amsterdam (VCWE-

2020–041R1, amendment 2021: VCWE-2021–018R1).

The Netherlands Autism Register works closely together with autistic individuals. Autistic individuals work in the NAR team and are also consulted through panels. The authors of this paper have no personal experience with alternative treatments related to autism.

2. Results

The 13 interviewees were a varied group (see Table 1). Each interviewee had a different experience of how they received a diagnosis and what treatments they had used. Seven participants had followed countless mainstream treatments with little success and had at last turned to alternative treatments. Four participants used alternative treatments in addition to mainstream treatments while one participant had never followed mainstream treatments and another preferred to try alternative treatments before considering mainstream treatments.

Five main themes and 14 sub-themes were identified (see Fig. 1 and Appendix B). The main themes were: (1) reasons for choosing alternative treatment, (2) treatment content, (3) experiences with alternative care, (4) outcomes of the vaccine-related treatment and (5) future directions for treating autism. These themes and their sub-themes are discussed and illustrated with quotes from the interviews. Appendix B contains additional quotes.

2.1. Theme 1: Reasons for choosing alternative treatments

Most participants did not select alternative care because they wanted to cure autism, instead other factors informed their decision. Twelve participants received treatment from an alternative practitioner to improve physical health problems, sleep problems, general well-being, stress and overstimulation (sensory problems). Only one participant sought a cure for autism. Interviewees thought it was worth trying alternative treatments for several reasons.

2.1.1. It's worth a try

Alternative treatments were usually seen as not very intense and easy to implement. Subsequently, all participants thought it would be worth a try, regardless of their personal opinion on alternative care.

Three participants made sure their alternative practitioner had some kind of medical training to ensure their capability.

"I've always looked to see if there was something of a medical background in there. That they were, for example, a medical doctor or whatever. But not that it was someone who has done a course in homeopathy..."

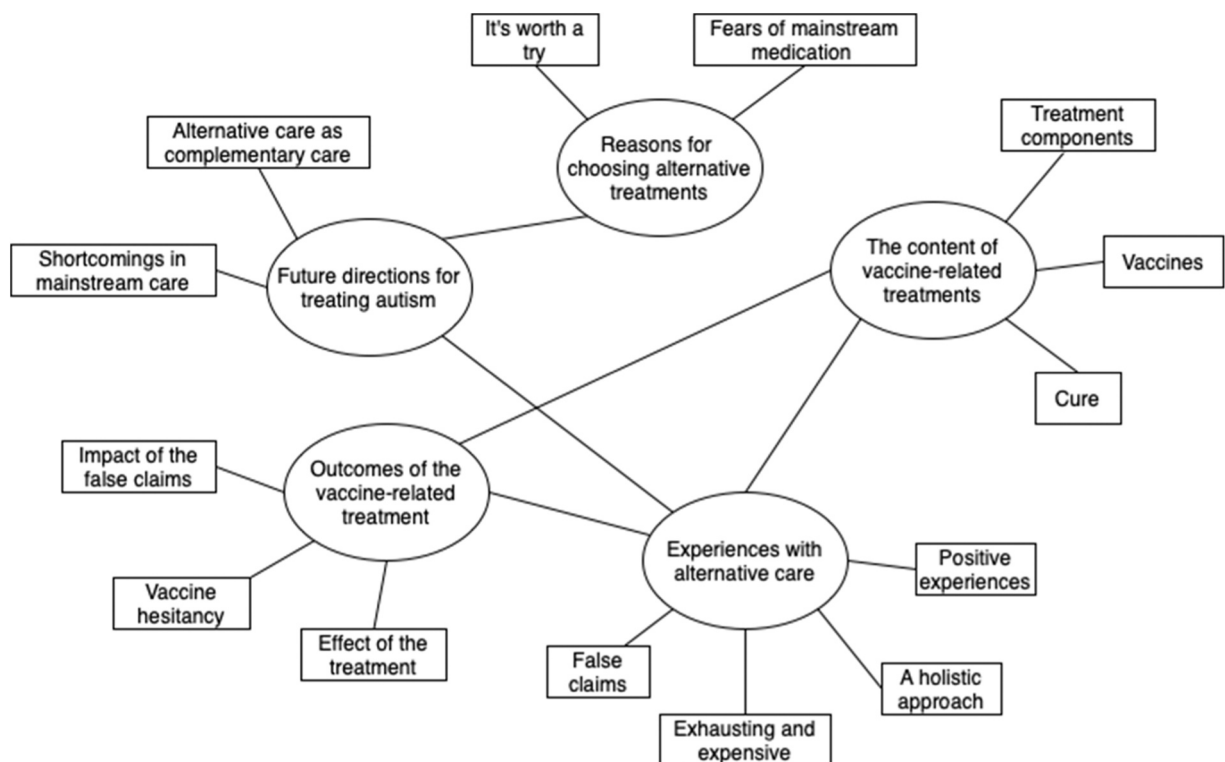


Fig. 1. Thematic map of main themes and subthemes. The connections show relations between the themes based on themes being consistently mentioned in tandem by participants.

For five participants alternative treatment was a last resort. When mainstream care had failed to produce the desired results, they turned to alternative care hoping they could finally find some relief. This was often the case when the autistic individual had multiple additional medical and/or physical complaints.

“...and then I was so desperate, I thought I’ll try anything they can come up with, just to get things a bit calmer at home.”

2.1.2. Fears of mainstream medication

Eight participants mentioned fears of mainstream medication, especially for young children. Including side- and long-term effects of the medications that were suggested by their mainstream doctor or psychiatrist (after non-medication treatments did not have the desired effects). They wanted to fix problems using alternative treatments first or refused to give (young) children mainstream medication at all.

“Then we consciously first looked into homeopathic remedies because we thought he is still so terribly young. We thought it was a bit scary to put methylphenidate and such in them at the time.”

“In itself I think homeopathy is a better way to give medicine, especially to young children, because the alternative was at one point- the psychologists in [city] was talking about, yes, antidepressants and medication that would reduce the mood swings, (...) and he could not tell me what the long-term effect would be.”

2.2. Theme 2: Treatment content

Participants ended up at the vaccine-related treatment through different circumstances, and experienced slightly different treatments carried out by different practitioners, all with their own beliefs on autism, vaccines and a cure.

2.2.1. Treatment components

Treatment consisted of a combination of homeopathic prophylaxis (a homeopathic dilution of a vaccine), nutritional advice, supplements, Bach flower remedies and other homeopathic remedies. In a few cases the vaccine-related treatment was combined with other practices such as massages.

“And yes then my son got all kinds of supplements of vitamin C citrate, fish oil, magnesium, and the detox of those vaccinations.”

“So that was: measuring my body, seeing what kind of nutrients I needed. I once had a kind of rock. There were just a lot of things. (...) And then she usually gave me minerals, vitamins and also homeopathic, those little balls, pills.”

2.2.2. Vaccines

The interviews showed that alternative practitioners told varying stories about vaccinations. Two practitioners were certain autism was caused by vaccines. However, most practitioners were not certain. Seven said vaccines could possibly trigger something in someone who has aptitude for autism or that the detox of vaccinations could improve all kinds of things in the body which would then in turn improve the child’s behavior.

“He did talk about that. And he said that – I remember when he said: ‘There are whispers about that, making that link,’ he wasn’t sure himself. He did take that into account, but he did look broader than that, yes.”

Four practitioners said there was absolutely no link between autism and vaccines.

“No, no, no. This lady is very clear: autism is a neurological disorder. It’s something you can’t do anything about. Or at least, it can’t be cured.”

2.2.3. Cure

Only two participants received treatment from a practitioner who claimed to be able to cure autism. All other practitioners said that there is no cure, but that their treatment could cause improvements.

“She’s said ‘Yes, it is said that autism can be cured, but I’m not a big fan of it myself. I don’t believe that myself, I don’t want to say I can cure your son’s autism.’”

2.3. Theme 3: Experiences with alternative care

2.3.1. Positive experiences

Twelve participants indicated that they were reasonably satisfied with the vaccine-related treatment, regardless of the actual effectiveness. They were especially satisfied with the practitioners, who were often described as friendly people who had a lot of attention for them and really listened. One participant was indifferent about the treatment.

"I really liked the guidance there. Very open, understanding, warm. So. And it wasn't said that we're going to solve this. It was really: we're going to see what we can do for my son."

"My first appointment was actually supposed to be an hour and I was there for a little over an hour and a half and that was no problem. So yes, she really took her time and it feels more like you are being listened to, in my opinion."

2.3.2. A holistic approach

Six participants explicitly mentioned that they liked how the alternative practitioner looked at the problem from both physical and mental angles, integrating them and taking the whole person into account.

"I also liked that he didn't just look at the things, at the limitations, because at a certain point you only have conversations about things that go wrong and everything they don't do correctly and that is very negative and he also looked at things that went well and he also took that into account in his search for the right medication and yes, really a holistic approach, I liked it, yes."

2.3.3. Exhausting and expensive

Three participants found the vaccine-related treatment tiring, mostly because it was in addition to mainstream care and because the whole situation was mentally tough and exhausting. Furthermore, the treatment was often not or only partially reimbursed by health insurance; seven participants said the treatment was expensive. Combined with the absent effect this sometimes resulted in termination of the treatment.

"Costs you a lot of money. Costs you a lot of energy. It costs you a lot of grief, because you hope for something that gets better; that works, that actually doesn't work. And you want to believe it. And that's what makes it tiring."

"With how we were regarding finances at the time, that was also a burden. (...) That, and too stressful, and on the expensive side. That combination, if it had been one or the other, I would have found a way out of it, but that combination at some point was something like: 'yeah, never mind'."

2.3.4. False claims

Ten participants were worried about improbable claims of alternative practitioners (in general) and their effect on parents and children with autism. Alternative practitioners put (parents of) individuals with autism on the wrong track by providing them with a false sense of hope for cure, and consequent feelings of guilt when this fails to materialize, or guilt about vaccinating their children in the first place.

"But they [homeopaths] claim very strongly that they can cure autism. That's something they just can't and shouldn't say at all. And with that, parents get, are put on the wrong track. (...) And if you are also told that all those vaccinations that he received as a baby, may have been harmful and therefore may have triggered the autism. Then you are also put in a position of guilt as a parent, so that you also want to have the feeling of like: no, I don't want that because I'm a loving parent."

"I am absolutely against people who claim that they can cure autism because I am convinced that is not possible and I think that you wrongfully give parents hope."

In addition, nine participants also said they would rather not receive treatment from someone who claims to be able to cure autism. Those participants didn't believe autism could be cured and therefore would not trust a practitioner who claimed to be able to cure it. When asked if the practitioner had ever said that the treatment could cure autism one respondent said:

"No, I don't think we would have stayed with her either. Then we would have thought she was too stupid. No, that wouldn't have my confidence..."

2.4. Theme 4: Outcomes of the vaccine-related treatment

2.4.1. Effect of the treatment

Six participants claimed that the vaccine-related treatment had benefitted them in ways unrelated to core autism symptoms. For another three participants it was unclear whether the changes they noted were treatment related. Participants mainly mentioned improvements in physical complaints and more peace of mind.

"And the eldest has had tablets (...) they helped him to get more peace in his mind, well that was of course, yes, that was fantastic, such a difference and he definitely used them for 6/7 years."

There were also four participants who said that, in the end, the treatment had little to no effect. One participant saw a strong physical reaction to the homeopathic prophylaxis and took this as a sign that the treatment was doing its job.

"At that time he was given grains a couple of times. And certainly, the first two times he had very strong physical reactions. That there was a fever, the sweating that increased a lot. Those kinds of things. That you could see it was doing something."

2.4.2. Vaccine hesitancy

Practitioners who made resolute claims about the link between autism and vaccines influenced the vaccination attitude and behavior of their patients. Three participants, who already had some doubts about vaccinations, became more cautious. Nevertheless, no participants refused to have their children vaccinated at all as a result of the treatment. One participant had not vaccinated her children before the treatment started anyway.

“Yes, because, in the first instance, we had our youngest daughter vaccinated very limitedly. When she was a baby, she only had the polio vaccination. And all- then you get the MMR as a nine-year-old I believe and DPTP again and then she did get the whole battery. But only when she was nine.”

2.4.3. Impact of the false claims

Seven participants said that the claims about vaccines and curing autism affected their perception of autism. Believing autism can be cured hinders the acceptance of the diagnosis. When the diagnosis is not fully accepted, the parents, and later the child themselves, may keep fighting against it instead of learning how to navigate life with the diagnosis.

“So what happens; people hope that you can cure it. That’s not happening. And the child or adult with autism themselves or the parents subsequently develop a kind of guilt complex. It could have been cured, and we didn’t succeed, so apparently, we’re doing something wrong. You know, I just think that- and then you keep fighting it all your life ‘because you can cure it’. So you don’t get to the core and learn to deal with it and make it part of your life.”

One participant said that she had received several vaccine-related treatments in her childhood. The above-mentioned false claims had led her mother to believe her autism could be cured. Looking back, the participant said she experienced the treatments as traumatic.

“She [her mother] did indeed try even when my diagnosis was not official yet, she sent me to a lot of things and I went to a lot of people because she wanted to make me normal again. (...) I think I can say that I have childhood traumas from that and that is why I have such an aversion towards those people. It just makes me really angry (...) that they can force that on someone else when they don’t know what it’s like themselves.”

2.5. Theme 5: Future directions for treating autism

2.5.1. Shortcomings in mainstream care

The positive aspects of alternative care stood out to all participants. The personal attention and holistic approach were much appreciated, and reported to be lacking in mainstream treatments where there is often limited time and practitioners only focus on their own expertise. Other complaints included a lack of communication between different practitioners, the fragmented structure of mainstream care making it difficult to find the right help and often participants were unable to find an effective mainstream treatment. Participants would like to have fixed points of contact and more personalized and customized treatment options within mainstream care.

“Yes, time, attention and, in the case of autism, fixed points of contact.”

“We simply couldn’t get any further in mainstream care anyway, we didn’t have any help there either. You just had to figure it all out yourself. (...) I don’t know if it is much different now because I now also hear from parents that they search for a long time before they find help ...”

2.5.2. Alternative care as complementary care

Seven participants proposed increased cooperation between mainstream and alternative care. They believe that alternative care should be used in addition to mainstream care for autism.

“But I think it just needs to be looked at with a much more open mind on both sides and maybe even more collaboration. Like, okay, what can we learn from each other? Yes, that.”

3. Discussion

This is the first study to look at the lived experiences of individuals with autism who have used vaccine-related treatments through qualitative interviews. The findings provide insights into the use of, and consequences of, vaccine-related treatments for autism and alternative care in general. Individuals with autism and parents of autistic individuals reported both positive and negative experiences with vaccine-related treatments. Positive experiences were mostly related to the holistic approach, time and attention available in alternative care, in contrast to mainstream care. Negative experiences centered around the false claims made within alternative care about vaccines causing autism and the curability of autism.

As suggested by previous studies (Höfer et al., 2017; Lindly et al., 2018; Lofthouse et al., 2012), there is a diversity in both alternative practitioners and the treatments they offer. Some had a medical background, e.g., a retired general practitioner, while

others had no medical training. Our subtheme ‘treatment components’ also showed this variety. Alternative practitioners’ views on vaccinations also varied, as can be seen in the subtheme ‘vaccines’. Some practitioners believed firmly in everything related to homeopathy and objected to vaccinations. Others were less opposed to mainstream treatments, in favor of vaccinations and pragmatic about what could be achieved through alternative treatments. Nevertheless, the majority of participants were falsely informed by their alternative practitioner that vaccines (partly) caused autism. The subtheme ‘vaccine hesitancy’ shows that claims like this can affect parents in their decision to vaccinate their child by causing them to hesitate. This is not surprising as recommendations from healthcare professionals may act as important predictors for vaccine acceptance (Dubé et al., 2013).

As with vaccinations, only a few participants received treatment from an alternative practitioner who claimed to be able to cure autism, shown in the subtheme ‘cure’. However, the claims about autism being curable circulating within alternative care, still affected and worried many participants. As evidence from the subthemes ‘false claims’ and ‘impact of the false claims’ shows, the majority of participants were worried about the effects these claims could have on (parents of) autistic individuals. These false claims affected participant’s perception of autism, gave them false hope and hindered the acceptance of the autism diagnosis. One participant perceived the vaccine-related treatments she underwent as a child to be traumatic when the treatment, against her mother’s expectations, did not cure her autism. This goal of curing autism seems to be a specifically harmful component of treatment. A cure for autism is not only unavailable, but also (according to many) not desirable (Leadbitter et al., 2021). Future research should continue to look at the implications of treatments that promise to cure autism and their effects on stigma. This includes various alternative treatments but also mainstream treatments like ABA that have been criticized for forcing autistic individuals to behave more neurotypical rather than helping them to thrive as an autistic individual (Izuno-Garcia et al., 2023).

Even though many participants were worried about the implicit effects of alternative treatments, most participants, despite the lack of effect, were still satisfied with their treatment and generally in favor of alternative treatments. This can be seen in the subthemes ‘positive experiences’ and ‘a holistic approach’. The positive aspects of alternative care have also been found in previous studies (Keene et al., 2019; Wang et al., 2018), often in contrast to mainstream care which lacked such aspects (e.g., time and attention; Levy & Hyman, 2008). The subthemes ‘it’s worth a try’, ‘shortcomings in mainstream care’ and ‘fears of mainstream medication’ show that people choose alternative treatments because they view them as a safe, convenient and pleasant option compared to mainstream treatments and especially compared to mainstream medication. This is in accordance with previous research (Keene et al., 2019; Levy & Hyman, 2008; Lindly et al., 2018).

Although participants were mostly satisfied with the alternative treatments, they reported no treatment effect on core autism symptoms and sometimes no effect at all, which is in line with the literature (Fuentes et al., 2020). The subtheme ‘effect of the treatment’ showed that those who saw any effect of the treatment, were likely to mention physical improvements and peace of mind (Keene et al., 2019; Wang et al., 2018). As the subtheme ‘exhausting and expensive’ shows, some participants described the alternative treatment to be tiring and pricey.

Overall, alternative treatments were used *in addition to* mainstream treatment (Lindly et al., 2018). Some participants also stated a desire for more cooperation between mainstream and alternative care as can be seen in the subtheme ‘alternative care as complementary care’. However, this was not always the case for mainstream medication which some participants were reluctant to give to young children (Keene et al., 2019; Lindly et al., 2018), here some participants wanted to use alternative treatments *instead of* mainstream medication.

A strength of this study is that it gathered information from different perspectives (parents of autistic children, adults with autism and parents of adults with autism). With the use of semi-structured interviews, we have explored in-depth personal experiences and gained valuable insights into individuals’ own narratives. However, the data did not allow for an analysis of the potential differences in perspectives between the three groups of participants. Furthermore, participants were selected based on negative experiences with vaccine-related treatment which affects the generalizability of the results. Nevertheless, selecting these atypical cases provided in-depth insights about phenomena not very well-explored so far.

The results from this study are also limited to the Dutch cultural setting. Other countries might have different perceptions of autism, healthcare systems and diagnostic approaches. Professionals’ view may impact people’s desire and attitude towards alternative treatments. Future research should take this cultural context into account. Furthermore, this study focused only on the experiences of people receiving the treatments. Stakeholders such as healthcare providers and policy makers, should be involved to reflect on their experiences and views on alternative treatments. Additionally, future research should explore the differences in perspectives between different groups of informants such as self-report and parent-report. Other factors such as socio-economic status or ethnicity could also influence the use of alternative treatments. These were not included in the current study but should be explored in future studies. Another factor that is important to treatment decision is availability and access to services. Infrastructural weaknesses of services and barriers to seeking support should be identified and investigated further to understand how they interfere with choosing alternative treatments.

Unfortunately, the mistaken belief that autism is (partly) caused by vaccines is still prevalent, especially among parents of autistic children (Chen et al., 2021; Davidson, 2017). Parents who believe toxins from vaccines could have contributed to their child developing autism, are more likely to be hesitant about vaccinations (Mensah-Bonsu et al., 2021). Vaccine-hesitancy and refusal constitute a growing concern (Pullan and Dey, 2021). The false claims made by vaccine-related treatments reinforce the social stigma around autism and hinder the acceptance of an autism diagnosis. These are possibly the most harmful aspects of vaccine-related treatments, and they ought to be highlighted more. The Dutch legal system focusses on freedom of choice regarding the use of (alternative) treatments. Without clear proof of treatments causing health damage, prohibition of these treatments is unlikely. Therefore, more supportive networks should be made available for parents with children first diagnosed with autism as well as sufficient resources to make a well-informed decision regarding treatment or support.

Furthermore, our study suggests that there should be more collaboration between different care services. Mainstream care may fall short in relationships with therapists, time, and attention. A holistic and interdisciplinary approach where more time and attention are integrated in practice could benefit parents and their autistic child(ren). Healthcare professionals' joint working encourages parents and adults with autism to keep away from ineffective and potentially harmful alternative treatments such as vaccine-related treatments. Clearer guidelines describing care pathways after receiving an autism diagnosis may facilitate informed decisions about treatment options, and help parents to feel less overwhelmed with the variability and diversity of treatment options (Frame and Casey, 2019).

CRediT authorship contribution statement

Kim M. Jonkman: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – original draft, Writing – review & editing, Visualization, Supervision, Project administration, **Maria Livanou:** Methodology, Resources, Writing – review & editing, **Manna A. Alma:** Methodology, Formal analysis, Resources, Data curation, Writing – review & editing, **Lotte Benard:** Methodology, Software, Formal analysis, Data curation, Investigation, Visualization, **Sander Begeer:** Conceptualization, Methodology, Validation, Writing – review & editing, Supervision, Project administration, Funding acquisition, **Elisa Back:** Conceptualization, Methodology, Writing – review & editing, Funding acquisition.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

The data that has been used is confidential.

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Appendix A Interview guide

Part I: Background

Can you tell me a bit more about yourself (and the person about whom you completed the questionnaire)?

Can you briefly tell me about which treatments you have followed?

Part II: Route to the treatment

Can you tell me more about how you found this treatment?

What was your reason for choosing this treatment?

Did you follow any other treatments during your CEASE treatment?

Part III: Treatment content

Can you tell me more about what the treatment looked like? What happened during the treatment?

Did the treatment ultimately benefit you? If so, how?

When was the treatment stopped?

Part IV: Satisfaction and damage

What did you think of the treatment? How did you experience the treatment?

What did your environment think of the treatment?

What did the practitioner tell you about the possibility that the treatment would cure autism?

What did the practitioner tell you about the role of vaccines in the development of autism?

Part V: Costs and insurance

Can you tell me something about the reimbursement by the health insurance?

Can you estimate the total costs of the treatment?

Part VI: General questions about alternative care

Why do you think people turn to non-mainstream or alternative treatments?

What is lacking in the mainstream care for autism?

And can you find this in alternative care?

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How does your experience with alternative treatments differ from your experience with mainstream treatments?

Do you think you could have achieved the same results using mainstream treatments?

What do you think of practitioners who claim they can cure autism?

Would you choose to receive a treatment from someone who promises to cure autism?

Appendix B. Main themes, subthemes and illustrative quotes

Main themes	Sub-themes	Illustrative quotes
Reasons for choosing alternative treatments	It's worth a try - <i>Let's see what it does</i>	"Yes, I went to a homeopathic doctor with all three of them, I really wanted to go to a homeopathic <i>doctor</i>, because, yeah, I haven't had very good experiences with a homeopath, I thought it was important that they have a medical background..." "And so she told me a few things about post-vaccination syndrome and Tinus Smits and his ideas in which she was trained... Yes, and then we also got into a situation- well, you know, what we're doing doesn't work either. If he accepts those grains to ingest, let's see what it does". "But yeah, so in our search we also ended up here. With a homeopath actually, to investigate whether he could help him with certain things and yes, he suggested a detox course and that wasn't burdensome for him so yeah, they were just some small grains so then I thought let's just give it a go. I have to be honest, I didn't have much with that beforehand, because I didn't think it would have come from the vaccination with him, but yeah, you're at a homeopath and he suggests that and you search and you think well maybe let's give it a try and I have to say that I didn't notice that much difference with him, before and after the treatment. No difference really, but okay." "But it's just a last resort. Natural remedies usually don't have any, or at least in my experience, there were never really harmful things. So, then it's like, well, okay it can't hurt, you know."
	Fears of mainstream medication - <i>I think homeopathy is a better way to give medicine, especially to young children</i>	"But that- I studied SPH [social pedagogical care]. And what was said at the time about Ritalin and just antidepressants and those psychotics and all that, and that they had a numbing effect on someone. That has always evoked in me a very big aversion to use it even in the slightest."
Treatment content	Treatment components - <i>She usually gave me minerals, vitamins and also homeopathic, those little balls, pills</i>	"He got some of those little balls and we had to - there was, I know, there was a certain order in it, you had to build it up a few days - I think - and yes until they were gone, I don't know exactly what that distribution was. In any case, it was not all at once you give him all of them, you had to build it up and yes that was it, it was really nothing more than that detox cure."
	Vaccines - <i>There are children who have become autistic as a result of vaccination</i>	"Nothing, no, I don't know what she thought about that. No, I do not think so. She says it's a genetic abnormality that you have too, well I don't, my husband and children. And yes, under the influence of stress, such a genetic abnormality opens up which means that characteristics of autism can emerge more extremely. So yes, I mean if she says that, she doesn't say 'autism is caused by vaccinations'." "I think he said, but it's been so long that I don't remember exactly, that could play a role in autism. And that there are children who have become autistic as a result of vaccination. I had the feeling from the start that this was not the case with my son."
Experiences with alternative care	Cure - <i>'Yes, it is said that autism can be cured, but I'm not a big fan of it myself'</i>	"She then said 'PDD-NOS will it be cured? Not in a very short time, but it will pass.' And that my son would like to keep having PDD-NOS because he thinks he wouldn't be smart otherwise. So yes, here I actually made a note that she said it would cure it." "He didn't say that. He did say about the negative effects that the vaccination could have, that you could possibly improve or solve that. Yes. That you can cure autism, he didn't say much about that."
	Positive experiences - <i>She really took her time and it feels more like you are being listened to</i>	"Yes, the detox course was fine. Good explanation also and it was just a nice person. In any case, you also received a lot of attention for your child. I noticed in mainstream that it is more according to protocol. And that here they really look at how your child is or how you are yourself. Really at the person." "Well, what I personally remember is that I really liked that I was being listened to. That you were taken seriously with what you encountered, with the complaints because the regular doctors just stopped, they were for his lungs, they were for his blood pressure and for his ears..."
	A holistic approach - <i>really a holistic approach, I liked it, yes</i>	"Yes and you were followed personally, as a person. So not like you have complaints A, B and C and things and that has to pass. No, then she says, well- she just wanted to know everything about, how is school going, does

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Main themes	Sub-themes	Illustrative quotes
	Exhausting and expensive - <i>Too stressful and on the expensive side</i>	she have friends, what does she do with sports and such. The whole person was just followed a bit more.” “Well he had been detoxed twice then and I still have- meanwhile they wanted all kinds of thing for me too. And I made a note somewhere that I also just said for financial reasons that I would leave it at that... Well, because the effect was not, well, very big. It also didn’t harm. But every time a consultation, plus grains, plus all kinds of oils and then the advice with all kinds of vitamin preparations that we either get through her or order from a shop. That at some point it- financially I was fed up.”
	False claims - <i>And with that, parents are put on the wrong track</i>	“What I also found difficult about CEASE was that if you say you can get better, that also says that you would be doing something wrong as a parent. (...) On the one hand it’s confronting, like I said, as parent you are assigned a role. Like it’s your fault, which I didn’t like. At that time it didn’t make me want to stop it, not that. But yes, I’ll stay there, it is something I find difficult.” Interviewer: “And what do you think of practitioners who claim they can cure autism?” Participant: “Yes, there should be a very large prohibition line on their door. They can’t say that. That’s just not true. It is offering hope to the people themselves but also the attendants/counselors around them and it is just nonsense. You have it and you were born with it and yes that is my idea.” Interviewer: “Would you undergo treatment from someone who, among other things, claims to be able to cure autism?” Participant: “No.” Interviewer: “No?” Participant: “No, because then he won’t understand. Then, no.”
Outcomes of the vaccine-related treatment	Effect of the treatment - <i>they helped him to get more peace in his head</i>	“Yes, well, helped, no it didn’t help, he didn’t start talking. What did help are all those behavioral therapies and the PRT.” “Much more peace in my body. I also had to stop eating a lot of things, which resulted in much fewer physical complaints. Yes... sounds a bit strange... but I had less clouds in my head... So, I had more of an overview.” “... Yeah, well that’s hard of course with that kind of homeopathic crap. ... Did it yield anything? Yes, maybe. But not something I myself can notice.”
	Vaccine hesitancy - <i>I did think about it then. Yes, is it wise to do it?</i>	“Indeed, I did think about it then. Yes, is it wise to do it? But because too little is known about it, I just went along with the vaccination program. Also for the next child. I think if more was known about is, the assessment would be different. It’s just that there is little evidence and little is known about it. That makes it hard.” “And then you actually start thinking about well maybe I should postpone because that’s what I did then: postpone the nine-year jab for a while. Because he was still having heavy asthma attacks, because I thought, yes, if the alternative doctor says: ‘don’t administer it if he is sick’, then I should just wait. I just caught up with it later when my son was 14.”
	Impact of the false claims - <i>and then you keep fighting it all your life ‘because you can cure it’</i>	“So on the one hand it’s good that there is that choice, but it’s just difficult for parents of children like my son. Because it’s just difficult. You go through a huge rollercoaster of processing. And that processing is now, now that he is almost 20, very advanced. But now we are entering other phases: when will he leave the house, can he still stay overnight, will he still be okay? Hey, he is looked at on the street like he’s a scary man, when he walks like that (makes noises) on the street. Always walks 10 m in front of me. They find it scary. So it’s- you’re just processing and I think that coping process is very vulnerable and those alternative therapies play into that. And I think that’s what’s dangerous about it.” “A lot of touching, that they’re all touching your body and your ‘blockages’ and that they are touching my head and my shoulders and my back and my chest. And... that you get a new rock or a new pill or new drops every time, which should help to make you normal again. And... if that doesn’t happen, because there’s no change in the situation, then your mother gets mad at you because you’re not doing what the man told you to do... That’s my experience.” “... She has sometimes said something, in the sense that she says well you can get rid of a lot of that. I’ve always been skeptical about that, because I don’t believe it at all. I think you have to remember; it starts with acceptance. And that’s kind of how she stood in it, it wasn’t a- But accept that it is like this and try to make it as nice and pleasant for them, here on this globe. But we can’t cure this no.”
Future directions for treating autism	Shortcomings in mainstream care - <i>We simply couldn’t get any further in mainstream care</i>	“Because you simply notice that there is far too little knowledge in the mainstream setting. And it has also been torn apart. At the GGZ [mental healthcare] they look entirely at the behaviour and the overload and such, but not at the body. And at the hospital they only look at the body and that is

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Main themes	Sub-themes	Illustrative quotes
	Alternative care as complementary care- <i>a much more open mind on both sides and maybe even more collaboration</i>	not interwoven. While in reality, it is woven together. And that's the missing thing. Sometimes they don't take a physical complaint seriously at the GGZ and in the hospital they cannot do anything with physical complaints that arise from overload. Even though they are actually there in the body." Interviewer: Yes. And what do you miss most in the mainstream care for autism? Participant: "Customization. I think that the group that is certainly also intellectually handicapped gets off very badly. There's a group that can't stand up for themselves, so that means parents or guardians have to. But there they have a very straight-forward look at okay, usually we do medication like this or medication like that and they are easier, or easy is not quite the right word, but it's less attuned to the person than it is for the people who do have a voice." "So, for example, I recently had a conversation with a psychiatrist at the specialist mental health service where the children are. He suggested to my son to, what's that called... well, to use a medicine for his concentration. And then I said well, we have just received a naturopathic medicine from the natural doctor for his concentration and we see that it's improving. And then the psychiatrist doesn't say, well, nonsense or something. He also read about it quite a bit himself and it's funny, we had a conversation about it. And then he also respects that we won't switch to those medicines. And I also have that myself, well if it is not sufficient and we think that there is more to be gained with ordinary medication through the psychiatrist, then we will try that too. My husband also did it, it worked well so you want that to complement each other." "I think it's very good that research is being done, because I think it can sometimes be very useful. Because some things belong to alternative things, while I think, yes, that can contribute quite a bit. Either it isn't reimbursed or- thing like play therapy are usually reimbursed I think, but that wasn't the case before either. You know, so I do think it's good to keep researching that in an objective way. Because otherwise, in advance, you'll be throwing out a lot of things that might have a contribution."

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